

GI Wanna Talk About Autism:

A Qualitative, Participatory Study of Gastrointestinal Symptoms in Autistic Adults

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Introduction

- Gastrointestinal (GI) symptoms are common in autistic individuals and can be disabling, yet almost all research has focused on the pediatric population.
- Very little is known about the experience of autistic adults with GI symptoms.

Study Goals

1. Describe the lived experiences of autistic adults with GI symptoms
 2. Develop recommendations to improve the GI health of this population
- Study uses a participatory approach in which a Community Board of autistic and non-autistic adults with diverse professional and lived experiences contributed to the study design, analysis, interpretation, and dissemination of findings.

Methods

Recruitment of interview participants

- Social media (Twitter, Instagram, Facebook); Local autism centers; Snowball sampling

Eligibility of interview participants

- Identified as autistic person/person on the autism spectrum (no formal diagnosis needed)
- Be 18 years of age or older
- Had gastrointestinal symptoms now or in past
- Live in the United States
- Understood spoken and written English
- *If autistic adult could not complete the interview by themselves, parent could help with interview or complete interview

Interview Format

- Four interviewers (2 autistic and 2 non-autistic researchers) conducted in-depth, semi-structured interviews
- All interviews took place via Zoom in video or audio format and were transcribed verbatim. Transcripts were reviewed by participants for accuracy and approval.

Qualitative Analysis (Interpretative Phenomenological Analysis)

- Five-person study team (3 autistic and 2 non-autistic researchers)
- Codebook was generated through an iterative process of individual transcript coding and group consolidation and refinement of codes.

Participants

- 21 autistic adults (19 w/ professional diagnosis) & 5 mothers of autistic adults
- Age: 18-50 years (mean 30); Age at diagnosis: 2-42 years
- Gender: 42% Men, 42% Women, 16% Non-binary, genderqueer, or gender non-conforming
- Race: 88% white (n=22), 4% Asian (n=1), 4 % Hispanic/Latino (n=1), 8% Missing (n=2)

Autistic adults report that GI symptoms...

- Can be disabling to many parts of life
- Sometimes, but not always, have identifiable triggers
- Are difficult to find quality healthcare for
- Require lots of planning and supports



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Funding and Acknowledgements

This work was supported by AIR-P (PI Holingue & Johnson) and ASF (PI Holingue).

This project is supported by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS) under award UT2MC39440, the Autism Intervention Research Network on Physical Health. The information, content, and/or conclusions are those of the author and should not be construed as the official position of, nor should any endorsements be inferred by HRSA, HHS, or the US Government.

Internal Review Board Approval was granted by Johns Hopkins University:
JHM IRB 00316729



Themes and Quotes

Theme #1: In many instances, GI symptoms have profound and extensive negative impacts on all areas of life

- "...I was skin and bones and I couldn't eat. I would nibble about three saltines a day. I didn't know why. I felt like passing out constantly. I would just lay on the couch and rot and I just couldn't eat. I couldn't function."
- "...I don't know if I'll be able to hold down a full-time job or not...Will I ever be able to date or do anything?"

Theme #2: Common triggers of GI issues include stress, sensory overwhelm, and changes in routine and food, though triggers were not always apparent.

- "That's been a frustrating part about it, is that it doesn't seem to be linked to anything specific..."
- "I do remember feeling bad, but it was from stress, because going anywhere, doing anything stressed me out because I was selective mute. That always just means pressure to speak, someone harassing you, strangers telling you your hair is beautiful and putting you on the spot. Life was just so extremely horrible. It was just unbelievably horrible that my only memories of doing anything are when I felt like I was going to vomit."

Theme #3: Most autistic adults and their parents described primarily frustrating and unhelpful healthcare interactions. They found the system difficult, unpleasant, and expensive to navigate and felt healthcare providers were often dismissive and did not offer useful diagnoses or advice

- "'I have yet to find a provider that has any idea how to help us.' (Parent of autistic adult)"
- "So I'm having a lot of these extra tests done and then it's getting really expensive. And I feel like if I had doctors that were more understanding of autism and neurodivergent individuals, that they would have a, I guess a better... What do you call it?...obviously I don't fit the box. So that's my struggle right now. Is that I'm having to actively find a doctor that is going to think outside the box because I've been dismissed as anxiety or drug-seeking or something else."

Theme #4: Autistic adults relied on medications, extensive planning and preparation, avoidance of triggers, and positive supports such as family or friends to help prevent and manage their symptoms.

- "Well, one of the things I do is do that [have a bowel movement], and also there are times when I take these antidiarrhea pills and also take Pepto."
- "One thing about my particular brand of autism is I'm always prepared for things. If I leave the house, is there something I might need that I never need, but I'm going to take with me anyway? I have all the supplies in your car that you'll ever need, and some of those things are GI things."